

TALKING POINTS
FOR
ACCEPTANCE OF "1988 OUTSTANDING RECOGNITION AWARD"
FROM THE
NATIONAL ASSOCIATION OF COMMUNITY HEALTH CENTERS
FEBRUARY 26, 1988

[Henry: The CHC people asked that you give a "pep talk" about the need for their members to work hard on Members while in town for their conference. They want their members to understand the severe budget constraints for FY 1989 and the importance of their active lobbying.]

Community and Migrant Health Centers are Well Respected in Congress

- o Community and Migrant Health Centers and the Federal Community and Migrant Health Centers programs have come of age. You are now considered to be an integral, and essential, part of our national government's efforts to meet the health care needs of our country.

-- You are highly respected for your work, for the quality of your service, and for your commitment to the people who live in medically underserved areas.

-- You are relied upon by Congress to reach the needy.

- o In 1983, when the recession produced large unemployment, Congress gave you additional funds to serve the unemployed.
 - o In 1987, we turned to you to serve the Homeless and to extend services to more children and pregnant women to reduce our unacceptably high infant mortality rates.
 - o And, now, the President's Commission on AIDS says you need more funds to help in our war on AIDS.
- Your importance grows every year as the number of uninsured Americans grows. There are now 37 million people without any form of health insurance.
- I congratulate you for your outstanding work.

You Can't Rest on your Laurels in 1988

- o You have a track record that warrants a significant increase in funding. But, in 1988, you cannot assume that Congress will give you what you need.
- There are large deficits projected for FY 1989 and beyond. The budget summit agreement provides for an

increase in discretionary spending of 2%. You cannot assume that your excellent record will be recognized with greater funding.

- But, you have many strong supporters in the Congress and on the essential Committees: Appropriations, Budget and the authorizing committees.
- You have the opportunity to capitalize on this support.
- While you are in town, I urge you to visit with the Members and Senators from your state. Tell them what you are doing and why continued and additional support is so vital.
- o I will be working with you on the legislation to reauthorize the Community and Migrant Health Centers programs. In our Energy and Commerce Committee and in Senator Kennedy's Labor and Human Resources Committee, your active presence is very important.
- o We share an important goal: high quality, primary health care for all Americans. In a time of limited budgets, our task is difficult. Let us recommit ourselves. Many Americans are counting on our success.

Thank You for the Award

- o I appreciate your recognition of my work. I work on your behalf and on the behalf of all those people in medically underserved areas of our country.

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STATEMENT OF CONGRESSMAN HENRY A. WAXMAN
AT PRESS CONFERENCE
ANNOUNCING AN ORPHAN DRUG GRANT FOR DR. JESS THOENE
MARCH 14, 1988

Good Morning. I wanted to participate in this press conference to pay tribute to some of the unsung heroes of our nation's effort to provide orphan drugs to the millions of Americans who suffer from rare diseases.

Let me start by congratulating Warner-Lambert, Biocraft Laboratories, and Mylan Laboratories, three of our nation's leading pharmaceutical manufacturers, for their generous contributions for the care of children with cystinosis and for their outstanding examples of corporate responsibility. I want to recognize Dr. Jess Thoene for his life-long dedication to the children he treats and for his work with the National Organization for Rare Disorders. And last, I want to recognize Erin Bowers and all the other young girls and boys like her who have acted so courageously in the face of their serious conditions. Erin, you set an example for all of us to admire.

I hope that through the interest of the press here today, the American people will learn about this important event and what has become the orphan drug success story.

The work of these wonderful people is not an isolated occurrence. It is part of a coordinated national effort to develop orphan drugs. It began in 1980, and now involves our government, private pharmaceutical companies that are brand and generic and large and small, independent scientists, voluntary disease organizations and millions of Americans who suffer with rare diseases.

In June 1980, when I conducted the first Congressional hearing on orphan drugs, the problems seemed insoluble. The only agreement that day was that rare diseases were taking a tremendous toll on the lives of so many people.

During the next 2 1/2 years, things slowly came into focus, with the result being the enactment of the Orphan Drug Act in January 1983. The law established the development of orphan drugs as a national priority. It provided financial incentives to pharmaceutical companies, federal research grants to individual scientists, and directives to FDA to promote orphan drug development.

We hoped to marshal the resources of our private pharmaceutical development system, but we knew that even with the Orphan Drug Act some drugs would never be profitable and might never be developed. The long term goal was to get the commitment of industry, government and